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Parent Focus

December 2005

State Schools for Severely Handicapped

Taking Care of Yourself

By Stephanie Brooks, Central Office

Parents or other caregivers of children with developmental disabilities face higher stress levels than those caring for children without disabilities. Research has shown that those parents with children who have autism or behavior disorders experience even higher stress than those whose children have Down syndrome.

There are many factors that can contribute to the ongoing stress:

- maintaining employment and locating reliable child care.
- financial concerns.
- the worry of dealing with unpredictable medical or other emergencies.
- the need to advocate for your child to obtain necessary services, funding, medical treatment, etc.
- dealing with health care professionals, medical insurance claims, government agencies and service organizations.
- sleep deprivation and exhaustion.
- lack of time to cover the needs of everyone in the family and to have private time.
- frustration in dealing with the physical and social skills limitations of your child and/or low self-care skills.
- social stigma or embarrassment when taking your child out in public, especially if challenging behaviors are present.
- unresolved sorrow and grief that this child is not and will never be the child you had expected to parent.

If parents cannot find ways to lower their stress levels, one of the long-term effects can be an inability to interact effectively with the child, often focusing on the disability rather than on the child as a person. You may lose your patience and your child may have a lower sense of well-being. Parents may suffer from depression or have other symptoms of anxiety, such as high blood pressure or ulcers. Prolonged stress can impact relationships with spouses, other children in the family and other family members, and can isolate parents from friends.

Obtaining short-term respite is one of the keys to maintaining balance in your life. As little as six hours per week has been shown to significantly reduce stress in a family. (See the article "Getting a Break: Short-Term Care Solutions" on page 3.) One of the temptations when the family obtains respite is to spend the time trying to play "catch-up" with everything that seems to need to be done. Better uses of the time are:

- Going on a date with your spouse. Do something you both enjoy and take time to focus on each other and not on being parents.
- Spend time with the other children in the family.
- Do something that nurtures you.

Ideas for keeping life in balance

(Many of these ideas were submitted by parents and home school coordinators.)

When you are home with your child and you need a break, you can:

- Make sure your child is safe (playing with a toy, listening to music, watching TV) and go into another room and calm down. Look at a magazine for a few minutes or read a couple of pages of a book.
- Have a one-minute break. Close your eyes and imagine yourself in a favorite location. Hear the sounds, feel the sun or the wind on your face, notice the smells. Come back relaxed.
- Breathe deeply and focus on your breath for a few seconds.
- Listen to music while doing chores or caring for your child.
- If your child is resisting the current activity, do something your child likes and you find enjoyable.
- Get some exercise. Climb stairs, dance to music, do some stretches. Go for a walk with your child. Or work in your yard and let your child help you. ►

Parent Focus

December 2005

State Schools for
Severely Handicapped
P.O. Box 480
Jefferson City, MO 65102-0480

Barbara Stevens,
Interim Superintendent



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Information concerning other available resources, programs, etc., is not to be construed as an endorsement by State Schools for Severely Handicapped for any specific product, organization or philosophy.

- Cook one of your favorite recipes.
- Find something funny on TV or on a video and laugh.

Talk about your feelings:

- Share your feelings with those family members and friends who will let you talk about your fears and worries.
- Find a local parent support group and attend meetings.
- Use the internet and join an online support group. E-mail parents who have children with disabilities similar to your child's.
- If things seem too overwhelming, obtain counseling. Some programs can send a counselor to your home.

Change your perspective:

- Focus on your child's abilities. Find activities at which your child can be successful.
- Develop a similar routine for most days. This helps you get through the day and provides needed structure for your child.
- Take life one day at a time. Try to keep things in perspective. Today's crisis may look insignificant in a month.
- Have a "to-do" list and prioritize everything. Know when to let something go and realize it's not important and can wait.
- Be organized. Keep all your child's records in one place, so you can easily track appointments, insurance claims, assessments, etc. Put down the family's keys, bags, etc. in the same place when you come home.
- Ask for help. Can someone else in the family help with some of the chores, or the cooking or shopping?
- Become knowledgeable about your child's condition and prognosis. Read books or research on the internet. Ask questions, so you'll know what to expect as your child gets older.

Get all the help you can:

- Talk to your child's service coordinator at the Regional Center and find out the respite options and other programs that could help you and your child.
- See if there are any programs that will take your child after school or on Saturdays.
- Involve your child in a sports activity or in camping.
- Trade caring for your child with another parent at the State School, so each family gets time for other activities.
- Welcome any help offered by family and friends.

And when you get some quiet time:

- Have one or more hobbies or activities you enjoy, such as gardening or reading.
- Look back to when you were younger and remember what made you happy. Perhaps you can take up one of those activities again. Have some fun!
- Focus on yourself and what you need to feel more balanced.

Check Your Emotional Bank Account

By Becky Brozovich, Home School Coordinator

Just as parenting can be rewarding, it also can be challenging. We all have what can be considered an "emotional bank." This is a place inside us where we store courage, strength and hope. These are the qualities which provide emotional fuel. Think of it as a bank account where we have to keep making deposits to keep the account open. We cannot withdraw a greater quantity than we deposit.

Deposits to our emotional bank are made through positive self-talk, having a "gratitude-attitude," surrounding ourselves with positive, affirming persons, attending a support group, having a hobby, taking care of our bodies and remembering our positive qualities.

Withdrawals from our emotional accounts are made when we give ourselves or others negative messages, or don't take care of ourselves physically or emotionally. Withdrawals are also made when we let ourselves become drained of energy by constantly taking care of others without taking care of our own needs.

Balance is important. Check your emotional bank account daily and keep a pulse on your needs. When we, as parents and caregivers, are emotionally tired and bankrupt, we cannot take care of others to the extent that we want to. We all need and deserve to keep our emotional banks full. ■

Getting a Break: Short-Term Care Solutions

Compiled from information submitted by Tracy Allen, Chokaio Benton, Becky Brozovich, Susan Cato, Alesia Cozart, Toni Dautenhahn, Robin Gruber, Sara Lewis, Teresa Nutting and Nancy Simpson, Home School Coordinators

Parents and other caregivers need regular breaks away from their developmentally disabled child to take care of personal business and relax. Some parents feel they must carry on and take care of their child at all times and that they are not entitled to private time, but this is a mistaken belief (see the cover article “*Taking Care of Yourself*”). It is vital for your emotional well-being and health that you get regular breaks. Your child also benefits from expanding his or her circle of friends.

Since finding suitable respite solutions may appear difficult, we put together these resources to show the choices available. But, before discussing practical suggestions, let's tackle a very real problem.

Fears parents have when leaving their child with a stranger:

- Child may be subject to abuse or neglect and child often cannot report either good or bad events to the parent.
- Caregiver may not fully understand child's needs or feelings and may misunderstand communication.
- Caregiver is not familiar with feeding or medical procedures (tube feedings, handling seizures, etc.).
- Caregiver may not recognize a serious problem.
- Child may display a behavior problem or have a tantrum.
- Caregiving is not of a high quality.
- Caregiver is scared of the situation and uncomfortable.
- Child is resistant to change and dealing with a newcomer.
- Parents have had past bad experiences or have read or heard about inappropriate care.

Suggestions for successful experiences with new caregivers:

- Ask others for suggestions on reliable caregivers, facilities and agencies who are experienced dealing with someone like your child. You may obtain ideas from other parents or staff at your school, your child's Regional Center service coordinator or a parent support group. Ask for references and check them out.
- Go to the facility or meet the person at the location where the care will take place (their home or yours). Decide if you feel comfortable at the facility and/or with the person or staff.
- Train the person or staff on anything they need to know about your child (feeding, care and medical procedures, behaviors, likes and dislikes, communication methods and meanings.) It is helpful to give them a basic list or booklet with important facts about your child.
- Let your child meet the person or staff for a short time while you are present. A successful method of breaking the ice is having your child complete a favorite activity with the newcomer. Try leaving the room to see if the person works well with your child while you are out of sight for a short time.
- The first time you use the facility or person, do so for a short period of time and then come home or pick up your child.
- If the experience continues to be successful, gradually lengthen the amount of time you leave your child.
- Once you locate a person who is compatible with your needs and those of your child, use that person frequently. Some families report that their child looks forward to being with a favorite respite person each week.
- Give the facility or person a phone number where you can be reached and/or contact numbers for family members to be used if there is an emergency or questions.
- If you don't succeed with the first or second person or facility, keep on trying. It is important for you to have a network of people you can trust to help with your child.
- One location has a childcare resource and referral program which matches the parent's needs with available providers and works with the child and potential provider until the parent is comfortable that the child's needs are being met. ►

Where to obtain respite care

Most parents reported that their own family members and close friends are their main resource. In addition, parents are using one or more of the following, especially if they don't have relatives living close by:

- Regular sitters will sometimes cover the evening or weekends.
- State school staff
- Church members
- A few parents have paired up with other parents at the State School and obtained free time by watching each other's children or by one parent taking both children to the movies.
- In cases of divorce or separation, sharing custody of the child gives the primary caregiver time for other activities.
- Before- and after-school programs, and programs that cover holiday periods. In some areas these are easier to locate once your child is over 18.
- Drop-in programs offered at least one Saturday per month by county agencies. Child can take part in various activities for up to six hours. These programs are free or low cost.
- Facilities or providers recommended and funded through the Regional Center or the local county developmental disabilities Senate Bill 40 (SB40) Board or other similar local agency.
- Where there are significant medical concerns, parents can request personal care attendant time through the Bureau of Special Health Care Needs (see the article on page 9). This program provides care in the home and can be added to the standard respite hours allowed. When requesting this service, parents must ask for "personal care" services and not for "respite" services.

Funding for respite care

The key step is completing the intake process for your child at your local or satellite Regional Center and developing a "person-centered" plan, which should include a request for respite services, even if you aren't sure you want to use these services immediately. Ask your child's service coordinator about the availability of respite in your area and whether you should also get on the waiting list for other agencies that may have additional funding and/or other providers. In some areas, parents need to be persistent in asking for the respite care they need.

The majority of families using short-term respite are benefiting from programs with names such as "Family Respite" and "Friends and Family," many of which are administered by the county SB40 developmental disability boards or similar county agencies. Such programs can be located through your child's service coordinator or by asking school staff for information. Each family is responsible for locating their own respite provider (often from a list of approved providers), or they can hire someone they know to come into the home or to care for the child in their own home. Funding can be given to family members provided they do not reside with the child. The amount of respite care varies. Programs operate by allotting each family a monetary limit or an hourly limit, either by the month or by the year. Typically, money and hours do not carry over from year to year and will be lost if not used. Common allocations are 10-20 hours a month or 290 hours annually, or between \$60 to \$85 per month or \$720 annually.

Emergency care

Any parent can face unexpected situations where the parent is unable to care for a child for a temporary period. Again, this is where the child's "person-centered" plan comes into effect. The parent should contact the child's service coordinator immediately for placement in a group home or similar facility until the parent is able to care for the child. Some locations have several group homes or residential facilities that may have vacant beds. Other locations have virtually no respite homes available and the emphasis will be on trying to keep the child in the home and bringing in respite providers. If you plan ahead with the service coordinator, you will know what services are available in your area.

One family reported developing their own emergency plan with a number of family members and friends who were in place to take over care of the child if the parent was unable to do so for a few days. Other ideas included calling nursing homes or group homes to see if they could offer a bed for a few days, with the parents paying the charges themselves. ►

Resources

For information about the Regional Centers and their satellite offices, call 1-800-364-9687 or visit their Web site at www.dmh.mo.gov/mrdd/help/regions.htm.

For information on the counties with Developmental Disabilities Senate Bill 40 Boards, visit their Web site at www.macdds.org/county_info.html.

Ask staff at your school for referrals to local resources.

Whooping Cough Makes a Comeback

*by Claudia Rampley,
Central Office*

If you have questions or concerns regarding the health of your child, please contact your school nurse or your healthcare provider.

Success Stories

One family was able to enjoy a week's vacation by careful planning and using their respite time wisely. The student was enrolled in an after-school program. The parents realized that several staff members were familiar with the student and his needs, so the mother asked staff if they could rotate and take the student home each day after the program ended, stay overnight in the family home, get him ready for school the next morning and put him on the bus. Rotations of staff also helped out in the family home at the weekend until the parents returned. This student had a need for a fixed schedule in familiar surroundings, so this plan worked best for him and avoided disruption of his routine. The respite care was mainly paid for out of the family's annual allotment of respite hours.

Other families in areas where respite care is allotted by the month have been able to combine it with a one-time extra annual allotment of time, to make up a two or three day time period when they can leave their child safely and enjoy a mini-break. This doesn't always work out each time, since the child can get sick or have a major behavior outburst, but the families report success on second or third attempts to set this up.

Overall, families seem delighted when they are able to orchestrate these breaks. It takes planning, time and effort to make it work, but the outcome for the family is worth it. ■

HEALTH

Steady increase in reported cases since early 1980's

- During 2004, nearly 19,000 cases of whooping cough were reported to the Centers for Disease Control and Prevention (CDC).

Two of the reasons for the increase in cases

- Children have their last routine vaccination shot when they are between 4- and 6-years-old. Immunization wears off in five to ten years.
- Previously vaccinated teenagers and adults are at risk for catching this disease.

Why this is a concern

- Whooping cough can kill infants. Infants and young children who haven't been fully immunized have a higher risk of catching this disease.
- Whooping cough can cause a lingering but hard-to-diagnose cough in teens and adults.

Facts about whooping cough

- It can occur at any age.
- It is a bacterial infection, with initial cold or flu-like symptoms that include runny nose, sneezing, fever and a mild cough. This is followed by "fits" of 15 to 20 coughs in a row which leave the individual gasping for air. The cough may make a high-pitched "whooping" sound.
- It is spread by close contact, when an infected person talks, sneezes, or coughs.
- It is contagious for two weeks before the cough appears and up to three weeks afterwards, unless treated.

If you think you or someone in your family may have whooping cough

- See a healthcare provider. The infected person may be given antibiotics. After five full days of taking the medication, the infected person should no longer be contagious.
- Let the school know if anyone in your family has a diagnosis of whooping cough.

New whooping cough booster injections available

- The FDA recently approved two new combination products as boosters after the childhood series.
- Boostrix is approved for ages 10 to 18 years.
- Adacel is approved for ages 11 to 64 years.
- Contact your healthcare provider to see if your child or anyone else in your family would benefit from taking one of these products. ■

Bedtime Ideas

by Becky Brozovich,
Home School Coordinator

When asked which time of day creates the most difficulties for their family, parents inevitably reply “bedtime!” This is the time of day when all family members are tired; they are wound-up from events of the day, while thinking about plans for the next day. Not all family members want to wind down at nighttime and some struggle with their internal clock.

Sleep Needs

Adequate sleep is very important to children’s learning and over-all functioning. A recent study funded by the National Institute of Health found that children deprived of sleep had levels of inattentiveness which were observable by their teachers and which had an impact on their learning abilities. Lack of sleep was also found to be related to memory problems and behavioral concerns. Several other studies have linked sleep deprivation with health problems.

While each child’s sleep needs vary, there are some guidelines for the hours of sleep needed according to age. The National Sleep Foundation recommends the following hours per day of sleep per age group:

- Ages 3-6: Between 11 and 13 hours
- Ages 7-10: Between 10 and 11 hours
- Ages 11-17: Between 8.5 and 9.25 hours
- Adults: Between 7 and 9 hours.

Quiet Time for Parents

In addition to sleep being important to meet children’s basic needs, bedtime is a crucial time for parents, so they can have some quiet time. This time is important for busy parents not only to catch up on last minute chores from the day and to organize the next day’s activities, but to rest and relax. Parents need to get enough sleep and to take care of themselves. Carving out an extra hour or two in the evening can go a long way toward helping parents replenish their reserves.

Parents taking good care of themselves is similar to flying on an airplane. The flight attendant tells us that, in the event of an air mishap, oxygen masks will drop from the ceiling. The initial instinct for parents traveling with their child is to take one mask and place it on their child. But parents are asked by the flight crew not to do this. Instead, they must put on a mask themselves first, and then attend to their child. The reason for this request is that if we do not care for ourselves first, we may not be able to care for our child.

Bedtime Routine

The need for a bedtime routine is important not just for children’s learning and health needs, or for parents to have quiet time, but also for the comfort and security of our children. All children, especially those who are developmentally disabled, thrive on structure and consistency. Routines of day-to-day life are vital to our children. There may be much of their world that they cannot see, hear, control or understand, but they can find comfort in knowing what happens when in their lives. This knowing creates a sense of security.

Initially, setting up routines and schedules can seem like a large task. However, being consistent in following through with this will reap rewards when the routine is established. Children may (and probably will) resist new rules at first, but when they see that the rules will continue, they will follow along.

A great place to start in setting up a bedtime routine is by thinking about what brings your child comfort. Is it a stuffed animal? Is it music? Is it hugs and kisses and cuddling? Is it reading time? This comfort object or activity can be used to help with transition from evening activities to bedtime and make the time enjoyable for your child.

Before setting up a bedtime routine and time schedule, set yourself a realistic goal. If your child is going to bed at 10:00 p.m. and you would like him in bed and asleep at 8:00 p.m., you will need to implement small changes, and work towards the 8:00 p.m. final goal. In this situation, set up the routine and expect him in bed at 9:45 p.m. After he gets used to the routine and is successful at staying in bed and going to sleep at 9:45 p.m., you can move the routine back 15 minutes, with bedtime at 9:30 p.m. and repeat the process until your child is ready to go to bed at 8:00 p.m.

In setting up a routine, the first step is to work out the time schedule. When will you need to begin the bedtime routine to have your child in bed and going to sleep at your initial goal time?

(Continued on page 8)

Using Social Stories and Picture Schedules at Bedtime

by Karen Wells,
Supervisor for Instruction

Social Stories

What is a social story and what is its purpose?

- A short story is written by parents and/or school staff to address a given situation specific to the child's needs.
- The story has a few pages and a few words on each page. Pictures that depict the words on the page are helpful to assist the child in understanding the story. Pictures can be photos, drawings or picture symbols. Photos can include the child if desired.
- The story provides information regarding who, what, when, where, and why to describe the given situation, skill or behavior.
- It helps the child gain a better understanding of the situation and the expected behavior.

An example of a social story is shown below. The pages of this story could be put in plastic cover sheets for durability and inserted in a binder. Times on small clock faces could be added to assist the child in understanding the times the routine is to begin and end.

Picture Schedules/Routines

What is a picture schedule and what is its purpose?

- A picture schedule is a set of pictures that show the routine to be followed in a given situation.
- Pictures can be actual photos, picture symbols or drawings. Photos can include the child, if desired.
- Words can be written with the pictures or just the pictures can be shown.
- The schedule provides the child information regarding the routine – when and what is to happen.
- It helps the child understand the situation, know what is to occur next, and what behavior is expected.

The same types of pictures used in the social story example could be used in a picture schedule/routine. The words could be eliminated. Pictures are kept loose and are best covered in plastic or laminated. They can be shown two at a time to show the child what is to be done first, then next, etc. A picture schedule could be used alone or in addition to the social story. The social story could be read to the child a few minutes before the bedtime routine is to begin, then the picture schedule/routine could be used as the child goes through the actual routine. ■

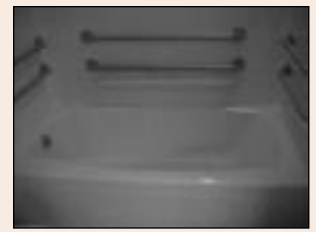
Example of a social story showing a bedtime routine.



Bed time.



I put my toys away.



I take a bath/shower.



I brush my teeth.



I get into bed.



I listen to a story.



Then, I go to sleep.

For some families this may be 45 to 60 minutes. Decide on a way to let your child know that bedtime is near. You could announce it every night, or give your child a picture showing his or her bed or a picture of someone sleeping, or point out the time on the clock. Then establish a standard routine, which could be: "First we put away our toys, then we shower and brush our teeth, then we lay out clothes for tomorrow, then we lie in bed quietly with our snuggly animal and read. Then lights go out at 8:00." Social stories and picture schedules are a couple of helpful tools for parents to use (see page 7).

Support the routine and schedule by setting the stage throughout your home for a quiet bedtime. Turn off or down television sets or music in other parts of the home, and keep lights around your child's room off or dimmed. Other children in the family should also have expected bedtimes and follow their own schedules.

There is the possibility that your child will challenge the new routine or test limits. Keeping to the routine and schedule consistently will keep testing to a minimum. It helps if you make bedtime a positive time where you focus on your child and share activities that your child enjoys. Some parents use reinforcements for adherence to rules. Reinforcements can be praise, preferred objects and/or activities. Bedtime can present challenges for families, but it can also be a time of togetherness and comfort! ■

Residential Summer Camps

*Compiled from information
provided by Robin Gruber
and Tracy Allen, Home School
Coordinators*

Now is the time of year to decide whether you would like your child to attend one of the Missouri summer camps in 2006. Some camps have registration deadlines of April or May. Others are very popular and sessions start closing as early as January (Camp Barnabas).

Tips for deciding on a camp:

- You know your child better than anyone else. You know your child's special needs and have developed special ways of helping him or her. This intimate knowledge should be the basis of your evaluation of any camp program. A good measure of whether a camp is right for your child is the staff's ability to understand and to answer your questions and concerns.
- Ask the camp about the program when the weather is bad; camp policy on homesickness, parents visiting and other concerns you may have; the possibility of arranging a car pool with other campers from your area.
- When you've decided on a camp, talk about it with your child and let your child know what to expect, especially if he or she needs help with dressing, eating or toileting. Your child will be relieved to know there will be someone at the camp to help with these needs.

Comments from families already sending children to camp:

One family recommended talking with other parents whose children have been to the camp, so that you know what to expect before you send your child. Other comments:

"This was (her) first time to be away from her family for any length of time. She only lasted two days, but that was longer than we thought. We will be trying again next year and sending her twin with her this time and see how it goes."

"He enjoyed it MORE than I expected. We enjoyed time off MORE than we expected. It always depends on who his volunteer is. The first year you could tell he had F-U-N! He would have stayed longer. The second year didn't go as well. His volunteer was a small female. She didn't do any activities with him like a guy would have. ...Every year is different." ■

Resources

We have posted a list of the camps, with details of their sessions, costs and other information under Parent Resources on our Web site at www.dese.state.mo.us/divspeced/stateschools.

If you would like a copy of this list, let your school know and they will send a copy home to you.

Special Health Care Needs Bureau

To find out more details about these programs, contact the main office.

• **Special Health Care Needs**
Department of Health and Senior Services
P.O. Box 570
Jefferson City, MO 65102-0570
Phone: 573-751-6246
Toll-free: 1-800-451-0669
www.dhss.mo.gov/SHCN

To find out if your child is eligible, contact these regional offices.

• **Cape Girardeau**
(573) 290-5830

• **Columbia**
(573) 882-9861

• **Kansas City**
(816) 350-5433

• **Springfield**
(417) 895-6900

• **St. Louis**
(314) 877-2850

The Department of Health and Senior Services operates this bureau to oversee two programs which can provide in-home health care services for your child:

Healthy Children and Youth (HCY)

This program is open to all Medicaid eligible children (birth to 21) who are in need of medically necessary services from Medicaid providers. Staff at the bureau can confirm your eligibility over the phone. Treatment is determined by the primary care provider. A service coordinator will assess your needs and make up a service plan, which will include the type of services needed, the number of hours of help per week and the expected duration of the plan. The service coordinator will then identify potential service providers from which you can choose. The most common services available are private duty or skilled nursing and personal care attendants. The coordinator will follow up with you to ensure you are receiving the services you need.

Physical Disabilities Waiver

This waiver provides home and community-based services to a limited number of individuals with serious and complex medical needs who have reached the age of 21 and are no longer eligible to receive services under the program above. To be eligible for this program, the individual must be a Medicaid recipient over the age of 21, with a federally-matched Medicaid eligibility code. He or she must have qualified for private duty nursing services before turning 21, and require medical care equivalent to the level of care provided in an intermediate care facility. ■



Special Olympics

Compiled from information supplied by Janet Elders, New Dawn State School, Linda May, Trails West State School, Dena Seamon, Autumn Hill State School and Stan Smith, Parkview State School. All these teachers are Special Olympics coaches.

In the last issue of *Parent Focus* we included some background on the Special Olympics organization. To encourage more families to think about getting their students and/or themselves involved in Special Olympics, we surveyed some staff who are coaches and some parents whose children are athletes. This is what we discovered:

What's involved if your child becomes a Special Olympics athlete:

★ Sports offered

A wide range of sports are offered in Special Olympics. There are activities for students who use wheelchairs, as well as for those who are ambulatory. Our coaches regularly offer: bowling, track and field, soccer, basketball, softball, bocce and winter games (snowshoe racing and cross country skiing).

★ Age of Athletes

Athletes can compete in Special Olympics as soon as they are 8 years old. Former State Schools students continue to participate in Special Olympics after they graduate from school.

★ Training for the events

- For state events, the athletes train for a minimum of eight weeks. The amount of training needed depends on the athlete's abilities. Typically, training is between an hour and three hours per week in one or more sessions. Less training may take place for a local or area event.
- Training may take place at the local State School or other available facility either after school or on Saturdays.
- Parents are expected to transport students to and from training sessions. Coaches emphasize that arranging transportation is not generally a problem and families do transport each other's children. Occasionally coaches will transport a student home. ►

Resources

If you are interested in getting your child involved in Special Olympics:

- Phone 1-800-846-2682 or visit the Special Olympics Web site at www.somo.org.

Ask at your State School whether there is someone who coaches or could give you contact information for the group in your area.

★ Attending local, area and state events.

- **Local events:** These take place in towns close to the State Schools. The time for events ranges from two to eight hours and parents transport their own children. There are generally four athletes to each coach.
- **Area events:** These are at cities which may be up to 50 miles away from the school. With travel, events can range from four hours to overnight. Parents, coaches and aides may transport the students. Again, there are four to six athletes to each coach. As with local events, there are some buddy systems with college or high school students volunteering to help athletes, and in some locations each athlete has a buddy.
- **State events:** These take place at different locations for each sport and are often across the state. With travel, the event takes between two and three days. Parents, coaches and aides may transport the students. There are one or two adults to four athletes.
- **Costs:** The main cost for parents is transportation or paying for gas money. Free accommodation and some meals may be provided for the state games, but parents should plan on paying for some of the meals. Local fundraising can reduce some of the costs. The school's PTO may fund the athletes' uniforms.

★ What coaches need from parents.

- Ability to work out transportation to training and events.
- Flexibility on practice schedules.
- Obtaining the athlete's physical examination on time.
- Willingness to let go of the athlete and to let him or her grow up.
- Trusting the coach and believing in their child's abilities.

★ Comments from coaches on the positive outcomes they have observed in students due to participation in Special Olympics activities.

It is common to see improvements in:

- Social skills
- Self-esteem
- Confidence
- Physical strength, motor abilities, gait, range of motion
- Focus, paying attention
- Independence, ability to be away from family
- Communication skills
- Self care abilities
- Behavior
- Team play ►



"I know that Special Olympics takes a lot of time – but the benefits of it, for our athletes and their families, outweighs all of that. To see how an athlete relates to his parents outside of our school environment is priceless. Every parent and family needs their "special" athlete to be involved in something. All the other siblings are involved in a sport or activity that the family is involved in, and Special Olympics has been the answer for our athletes."

— Dena Seamon,
Physical Education Teacher
and Special Olympics coach,
Autumn Hill State School



“(Child’s coach) helped us realize that (child) was capable of doing much more than we gave him credit for. And he truly loves it! I believe it has helped him to realize many goals, physical and mental, that he may not have cared about before.”

Advice to other parents: “Do not hesitate! (Special Olympics) fosters a sense of camaraderie, self-esteem, confidence and gives them a reason to try their hardest to accomplish the goal, a goal they can see and hold, the medal!”

Additional comment: “... I am doing everything in my power to see that he gets all the opportunities to experience everything that a child without disabilities has. And that includes the spirit of competition.”

— Parent of Special Olympics athlete

Comments from parents with children in Special Olympics

★ Concerns of parents before child began competing and how these were resolved.

- Child was in the habit of running off, so the parent was concerned the coach would lose her child at state events. Parent gradually relaxed, especially after watching how the coach worked with her child at area events.
- For parents with concerns about feeding and other self-care activities, they let their children attend local and area events, where they can volunteer and help out with these activities.
- One child initially was in a wheelchair, wore diapers and was a finicky eater. The parents wondered how he could participate physically and whether he would like it. (This child became ambulatory before he competed in the events.) The parent credits the coach as having vision for this student and persuading the parent that there were activities in which this student could participate. This coach also kept the parent well-informed on potential risks in any of the activities.

★ Positive outcomes for the child.

- Opportunity to be in a safe environment and to “belong”.
- Gaining physical strength; playing and running much more at home.
- Being with peers and having fun.
- Learning patience by waiting for events.
- Making friends, interacting with others.
- Following directions.
- Learning the rules of different sports activities.
- Learning the routine at events and helping out new athletes and their parents.

★ Reactions of athletes when attending events.

A number of the athletes are non-verbal, so parents are reporting what they see as their child’s reaction.

- “(Child) has great enjoyment in his every competition. It is always a great moment to watch how solemnly he accepts his medals on the victory stand.”
- “She likes to go and loves it a lot.”
- “... his excitement in going and joy in winning are enough to satisfy any doubt anyone could have. He loves the cheers and “pats on the back” he receives, no matter what the outcome.”

★ Advice to other parents thinking about letting their child enter Special Olympics.

- “Give it a try; just do it.”
- “Become involved.”
- “Get to know other parents at the events.”
- “... participate. All efforts are honored, all who participate are winners.”

★ Benefits for athletes’ families.

- “His siblings have gained a knowledge of many types of disabilities and this helps them when at school, or out in public, to be empathetic and not afraid to approach others with disabilities.”
- “It’s one place you can go and feel welcome. For the whole family, it’s a nonjudgmental atmosphere. That helps us all relax a little.”
- One family has benefited from interaction with other children and parents. They enjoy seeing community volunteers experience their children and their gifts.

Thanks to the parents who took time to respond to our survey and to share how they feel about their children’s participation in the Special Olympics. ■

Sharing Our Strengths — A Support Matching Network

Workshops and Trainings

PARENT RESOURCES

This network offers parents of children with developmental disabilities the opportunity to obtain a parent to parent match, where parents share their experiences, listen, and help each other by providing information and emotional support. Mentors do not provide medical advice or counseling.

If you are interested in this network, you can contact them at 1-800-773-8652 or fill out the online application form at www.sharingourstrengths.com. You will be contacted by phone and asked about your situation and about the type of match you would like. These matches can be based on type of disability, geographic location, or particular concerns such as treatments or behavior issues. The mentors may be other parents or extended family members of someone with a disability, or a person with a similar disability or a professional.

The network finds as close a match as possible to your needs and then provides that person with your phone number or email. Most contacts are made by phone, but some parents use email. The mentor will attempt to contact you within a couple of days. A coordinator will check with you periodically to see if the match is helpful, or whether you would prefer a different person as your mentor.

This service is free and confidential. ■

MPACT Training for Parents

- **January 21, 2006** — *IDEA Boot Camp* (special education law, understanding the IEP process and disagreement resolution processes)
Nevada Community Center, 200 N. Ash, Nevada, Mo.
9 a.m. to 5 p.m.
- **January 23, 2006** — *Bullying*
St. Louis Special School District, 12110 Clayton, St. Louis, Mo.
9 a.m. to Noon or 6 p.m. to 9 p.m.
- **March 6, 2006** — *Positive Behavior Interventions*
St. Louis Special School District, 12110 Clayton, St. Louis, Mo.
9 a.m. to Noon or 6 p.m. to 9 p.m.
- **March 10, 2006** — *Transition to Empowered Lifestyles*
St. Louis Special School District, 12110 Clayton, St. Louis, Mo.
9 a.m. to Noon or 6 p.m. to 9 p.m.

For more details, call 1-800-743-7634 or check their Web site at www.ptimpact.com, then choose Training.

Other Training

- **February 23-25, 2006**
Midwest Symposium for Leadership in Behavior Disorders Annual Conference
Presymposium Workshops: February 23, 2006 (9 a.m. to 4 p.m.)
Main conference: February 24, 2006 (7:30 a.m. to 6:30 p.m.)
February 25, 2006 (8 a.m. to Noon)
Where: Hyatt Regency Crown Center, Kansas City, Mo.
Cost (*Pre-registration*): Main conference (\$85)
Entire conference with workshops (\$100)

For more details, call (913) 599-3311 or www.mslbd.org. Some assistance is available to parents. ■

STATE SCHOOLS FOR SEVERELY HANDICAPPED
Missouri Department of Elementary and Secondary Education
Web site: dese.mo.gov/divspeced/stateschools/

NOTE: If you have items of interest for the *Parent Focus*, please call 573-751-0706 (Missouri Relay 800-735-2966) or forward them to: Stephanie Brooks, State Schools for Severely Handicapped, P.O. Box 480, Jefferson City, Missouri 65102-0480. E-mail: Stephanie.Brooks@dese.mo.gov